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ABSTRACT

As the AIDS epidemic continues, the number of children affected by AIDS continues to increase. Mental health professionals must begin to identify explicitly the special situational factors of AIDS and how they influence the grief process. In addition, the innovative use of mental health services must be considered, such as implementation of support groups for these children in nontraditional settings. Work with the extended family is critical because these adults represent the new caretaker to whom these children must attach and with whom they will identify. Topics covered in this special report are: grief work with children; children of parents with AIDS; and treatment considerations. Contains 13 references. (JBJ)

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Special Report

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Counseling for Children Who Have Lost Loved Ones to HIV/AIDS

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Introduction

Loss is a universal experience with which every person copes during the course of his or her lifetime. Losing a parent is a unique event with its own particular vicissitudes: Each person's reaction to such a loss depends on his or her psychological make up as well as the response of others to the death.

The current AIDS epidemic has deeply affected the necessary working through of grief. The tension generated by the AIDS patient's sudden bouts of illness, interrupted by abrupt and short-lived recuperation, influences the surviving family members' consideration of their imminent loss. The stigma surrounding AIDS, its symptoms, and the nature of its transmission also influence the bereavement process of families affected by AIDS. Mental health professionals must take into account the particular factors surrounding AIDS when providing services to children and families who experience its devastating impact.

In this context, children affected by AIDS often have been neglected in receiving services. Because they are not medically afflicted, frequently they are not identified as patients and, consequently, do not receive help. However, the numbers of children directly affected by AIDS—generally through a parent or caretaker's contraction of the human immunodeficiency virus (HIV)—continues to grow, particularly due to the increasing number of women who are infected (Centers for Disease Control and Prevention, 1994).

Grief Work with Children

The psychoanalytic literature on bereaved children is extensive. Theorists such as Wolfenstein (1966 & 1969), Pollock (1962), Altschul (1988), Furman (1974), and Bowlby (1980) have described in detail factors integral to successful grief work.

Children who have lost or are in the process of losing a parent require care and support from the other adults surrounding them, creating what Winnicott (1960) termed a "holding environment." Such a setting allows for the expression of feelings concerning the loss (e.g., anger or sadness) without repercussion. Also, these children need reassurance that despite the tragic event of the loss of a parent, their basic needs (food, clothing, and shelter) will be met.

The new home environment, immediately prior to or following parental bereavement, also should help the child transfer positive feelings to the new caretaker. In this new setting, the child may begin to form and consolidate identifications with the lost parent, which ultimately may help the child with future development. The secure confines of the new home may permit the child tentatively to explore his or her ambivalence about the loss—a process that Freud noted is inevitable in mourning (Freud, 1917).

A further consideration for grief work is the developmental level of the child. Younger children may view death in a more concrete fashion, perhaps harboring the belief that death is reversible. An older child or adolescent will conceptualize the parent's death in a more objective fashion, understanding all too well the harsh reality of the enduring nature of the loss. These maturational differences significantly affect how the counselor should speak to children about death and loss.

Children of Parents with AIDS

Childrens' need for stability and support following a loss has been well documented (Furman, 1974; Wolfenstein,

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1966). Furman (1974) warned against a breach in attachment following a loss as the child relies on adults for love, support, and maintenance of basic needs. Such a gap in attachment or caretaking may lead the child to identify pathologically with the dead parent rather than beginning to form positive connections to the new adults in his or her life.

However, children of families within which AIDS has claimed a life are often shuttled back and forth between various relatives and foster care placements with little or no time to form attachments. They may be separated from supportive caretakers and sent to live with family members with whom they have no relationship. Such moves may involve the child leaving a familiar home, school, and neighborhood with concomitant loss of social networks and supports. These dramatic and abrupt changes—not uncommon in many of these cases—may further compel the child to maintain a tie to the lost parent who, sadly, remains the one psychological constant for him or her. Later attachment to new figures involves a complicated undoing of this tie to the dead parent, and the child may be seriously affected as a result.

Adults surrounding children of parents with AIDS often cannot tolerate the expression of the children's feelings concerning the loss. This may be derived from the adults' own shame, discomfort, and unresolved feelings about AIDS. Elizur and Kaffman (1982) demonstrated that bereaved children struggle initially with cognitive mastery of loss, which may involve approaching adults with many questions about death. If the adult is uncomfortable with any discussion of death or AIDS, he or she may not permit the child to begin to comprehend the loss in intellectual terms, which often paves the way for a deeper, emotional understanding—an ultimate acceptance of the loss. The adult's discomfort may reflect familial prohibitions against talking about the dead parent, who contracted the illness through high-risk sexual intercourse, intravenous drug abuse, or both. The family may not allow discussion of the dead parent, leaving the child with many unanswered questions, inchoate feelings, and no forum in which to express these concerns.

Secrecy on the family's part may lead the child to adopt denial as a protective measure. Wolfenstein (1966) described one girl who explained the initial denial of her mother's death by saying, "If my mother were really dead, I would be all alone." A child affected by AIDS may present to a counselor and chat amiably about school and favorite television shows while conspicuously omitting any references to his or her parent who recently died of AIDS. The loneliness these children may feel can be perpetuated by the surviving adults who refuse to discuss the loss. Grandparents (who are often the new caretakers) may be so enraged at their children for their intravenous drug use that they do not permit others to mention the names of their deceased sons or daughters. The children in these families may steadfastly refuse any acknowledgment of their lost parent in counseling sessions, thereby replicating the secrecy and intolerance of any expression of longing and sadness.

The issue of identification with the lost parent, so necessary to the mourning process (Freud, 1917), may be influenced by the death of a parent to AIDS. Parents often are integral to early identification processes (Jacobson, 1965). When the parent has AIDS, the child may feel ashamed and ostracized and perhaps wonder if he or she will eventually contract the disease. Unfortunately, such pathologic associations may be reinforced in schools. For example, upon learning that a child's parent has AIDS, teachers may begin to question their routine physical contact with the child, even if the child is HIV-negative. These reactions will consolidate for the child the identification and pejorative connection with the parent who is ill. This identification with the parent's illness also may affect the child's sense of his or her own vulnerability and its connection to body image.

Some parents with AIDS (particularly those who contracted the illness through drug use) may have neglected or abused their children. This can adversely affect the identification process, because the child's rage and anger may predominate and lead to serious behavioral difficulties that reflect the child's anger, grief, and identity crisis. For example, one boy presented with the self-destructive symptom of puncturing his arm with pins. This dramatic act served to demonstrate his anger at and identification with his mother, who was an HIV-positive, intravenous drug user.

Wolfenstein (1966) noted how children often will idealize a lost parent. However, children of parents with AIDS struggle with idealization. They may remember happier times spent with their parents but concurrently recall being taunted by schoolmates and neighbors because of their parents' disease, experience anger at their parents for neglect and/or intravenous drug use, and feel normative rage at the parent(s) who abandoned them through death. Such a confusing conglomeration of feelings casts a shadow over the idealization that Wolfenstein (1966) recognized as a normative aspect of the bereavement process.

Wolfenstein (1969) further described the rage present in bereaved children that results from ambivalence toward the lost parent. In children of parents with AIDS, this ambivalence may be heightened as a result of anger at their parents for drug use, neglect, and shame. This rage may translate into severe behavioral difficulties.

Treatment Considerations

Two important prerequisites for successful grief resolution in children have been noted in the literature: the availability of an adequate parental substitute, with whom the child may forge a new connection; and a constructive, positive identification with the lost parent (Wolfenstein

1966 & 1969). A third vital component is the establishment of open communication.

Finding an adequate parental substitute for children of parents with AIDS may be difficult. Much of the literature on grief work with children is predicated on the assumption that despite the loss of one parent, there is still another parent alive. For children of families with AIDS, there is no such certainty, and, more often than not, the family was a single-parent one. The extended family, then, becomes critical for these children. However, the family members usually are dealing with their own issues of anger at the dead parent. Therefore, treatment must involve the family members so that they do not redirect their rage and grief at the deceased parent toward the child.

The new generation of caretakers for many of these children is, paradoxically, the older generation—their grandparents, who may require support concerning issues of rearing younger children later in life. Helping these adults understand *children's* expressions of grief (as opposed to adult norms) often may help solidify the connection between child and caretaker. For example, a child who steals and hoards food simply may be expressing his or her feelings of deprivation and wishes to be nurtured. A therapist may help the grandparent implement interventions, which, in turn, may help decrease this troubling behavior on the child's part.

The adult caretakers also may help the child differentiate from the lost parent, while concurrently promoting positive identifications. These children often adopt behaviors similar to those of their parents. Helping the new caretakers to allow the child to develop more positive identifications with the lost parent generally results in a reduction of problematic behaviors. Often, this requires a good deal of work because the grandparents' anger at their own daughter or son may be so great that they portray her or him in a negative light to the child. By the adult caretakers relating more positive anecdotes about the lost parent, a benevolent identification can be fostered in the child.

The aura of secrecy surrounding AIDS in our society makes open communication within the family critical. It will permit the child safely to express emotions. A further benefit is the child's experience of containment by the adults who allow the child this important emotional outlet in a stable home environment.

Therapy can help the child understand the universality of his or her responses to loss. Many children believe their reactions are shameful and attempt to hide them, although such diversionary tactics usually result in symptoms of grief. By demonstrating to these children that they are not alone, they can often find relief from shame.

One significant treatment modality for alleviation of feeling alone in one's reactions is group therapy. Aronson (1994) delineated several therapeutic factors in group work with children of families affected by HIV/AIDS. Many of these factors are relevant to individual work as well. These factors include universality, obtaining information, learning new ways to cope, as well as general provision of support.

Universality, as described by Yalom (1975), is a key therapeutic factor. Helping children to understand that they are not alone in experiencing the loss of a loved one can establish a commonality among group members. One girl hesitantly mentioned that each week she passed by the cemetery where her mother was buried. Two other girls in the group acknowledged that they did the same but were fearful of revealing this lest it be considered too morbid. This sharing of information ultimately led to the group members' feeling less isolated and alone with their difficult circumstances.

Imparting information is another important therapeutic factor. As previously mentioned, many families do not welcome discussions about AIDS. Consequently, many children are left with unanswered questions; this is particularly striking in light of the nationwide efforts to educate school children about AIDS. In one group, a boy asked if AIDS and cancer were the same illness; another boy asked if cancer could be transmitted through sex. Allowing direct discussion and providing information can be crucial to removing the veil of secrecy around this taboo subject. However, such discussions must account for the child's developmental level. For example, talking to young elementary school children about AIDS and death in abstract terms will only serve to confuse them further and possibly inhibit them from future discussion.

The development of adaptive coping strategies is another critical factor of the therapeutic work. Children of parents with AIDS often demonstrate behavioral problems in school. They may become depressed, withdrawn, or truant. Moreover, they may act out or serve as class clowns. Anger may color their peer interactions. Teaching these children about their emotional reactions and how to identify individual stressors is an important first step toward teaching them to manage their behavior and cope with the difficult aftermath of a loss.

Confidentiality, always an important component of any therapeutic intervention, is a particularly delicate issue when working with children whose parents have contracted or died from AIDS. Children can be very self-conscious regarding any difference that distinguishes them from their peers, and the counselor must take special care—particularly in school settings—to respect this need for privacy.

Concluding Remarks

As the AIDS epidemic continues, the number of children affected by AIDS continues to increase. More and more of these children are presenting at mental health clinics for services. Mental health professionals must begin to identify explicitly the special situational factors of

AIDS and how they influence the grief process. In addition, the innovative use of mental health services must be considered, such as implementation of support groups for these children in nontraditional settings—i.e., schools and adult AIDS services (Aronson, 1994). It is within these venues that children in need of mental health services can be reached most easily. Work with the extended family is critical because these adults represent the new caretakers to whom these children must attach and with whom they will identify. Helping these families to create a secure atmosphere will provide these children with the necessary setting and tools with which they may reach an understanding of the issues surrounding their parent's death, overcome their shame, and, ultimately, mourn their loss.

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